

The Australian Childhood Vision Impairment Register

May 2011 Update!

★ Latest ACVIR report

Currently there are 380 children registered with the Australian Childhood Vision Impairment Register – thank you to all of the wonderful families who have taken the time and effort to do this!

Below is a report of the 278 children who we have complete data on – hopefully the rest will come in soon. Of the 278, 40% are girls and 60% are boys. 40% of children are aged 0-6 years; 42% are aged 7-13 years; and 18% are aged 14-18 years. Read on to get information on our most common findings – remember these are uniquely Australian and this is the first time we have been able to report on data like this – you and your child are making history!

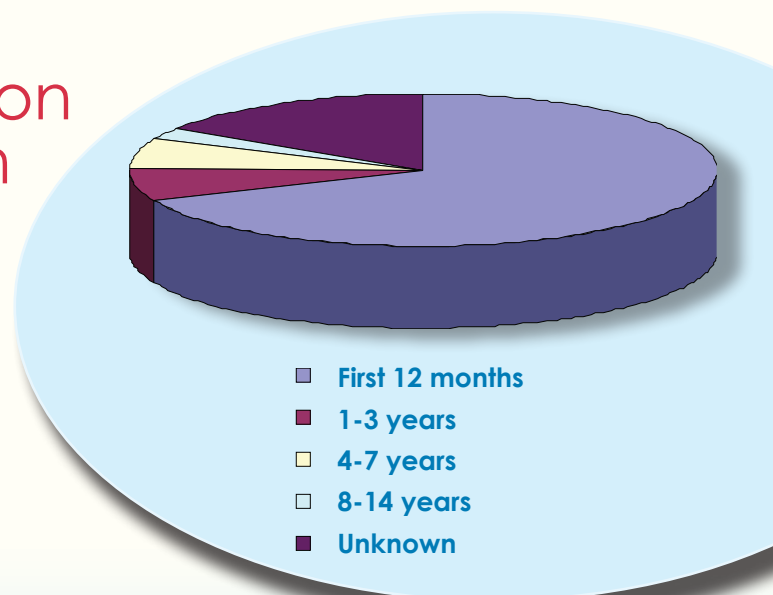
Where have the registered children and their parents been born?

11 registered children have been born overseas with the most common country being England and New Zealand. 24% of fathers and 18% of mothers of registered children have been born overseas. The most common countries of their births are England, New Zealand and Lebanon.

77% of registered families speak English as their main language. The next most common language spoken at home is Arabic.

When were eye or vision issues first suspected in registered children?

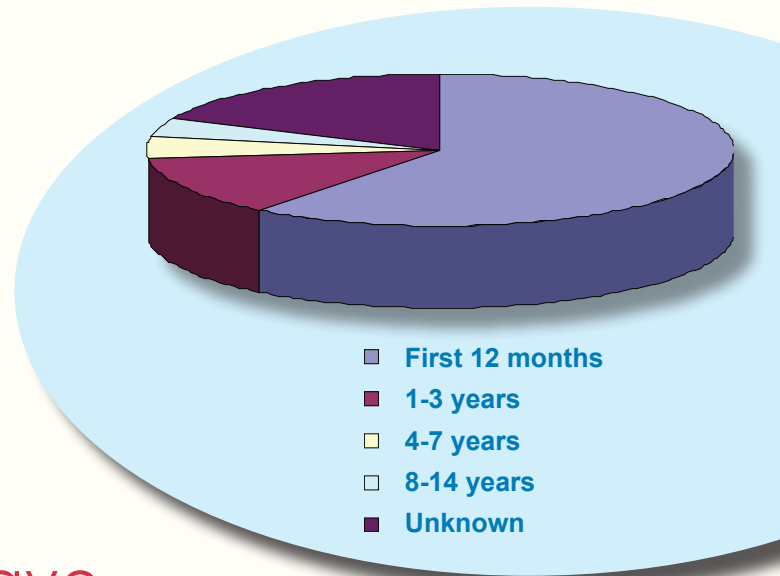
This diagram to the right shows the age that families first thought their child might have an eye or vision issue:



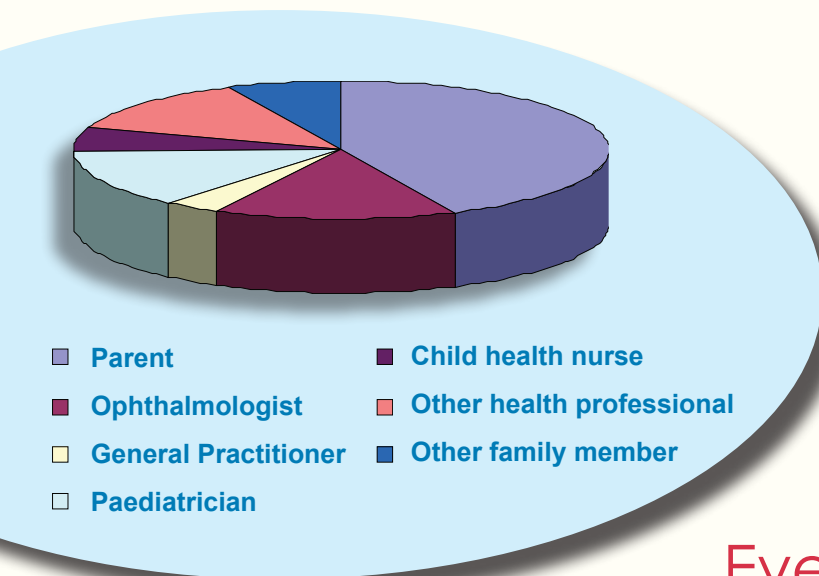
When were eye or vision issues first diagnosed in registered children?

The diagram on the right shows when families report their child was first diagnosed with an eye or vision issue:

It is good to see that most children who families suspect have problems are being diagnosed early so intervention can start.



Who first alerted the family to the fact the registered child may have eye or vision issues?



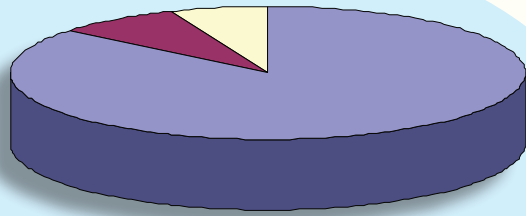
The most common person to be concerned about a child's eyes or their vision is the child's parent.

The diagram on the left shows this and the other people who first alerted the family that the child may have eye or vision issues:

Eye and vision conditions in other family members

It is interesting that 80% of registered families reported another family member with a similar eye condition to their child.

Have registered children been born around their due date or prematurely?



- 37-40 weeks
- 30-36 weeks
- 23-29 weeks

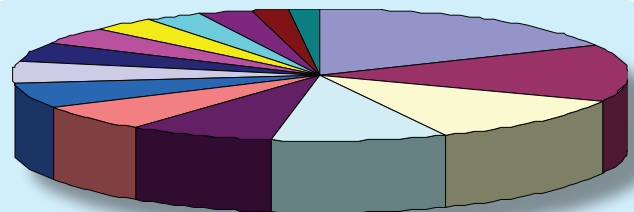
The chart to the left indicates the common gestational time that registered children were born. A baby is considered full term from 37-40 weeks. So most children have been born full term, however there are also some very premature babies on the Register.

How many registered children have had eye operations?

26% of registered children have had an eye operation of some kind and 3% children have an artificial eye.

What are the most common eye and vision problems in registered children?

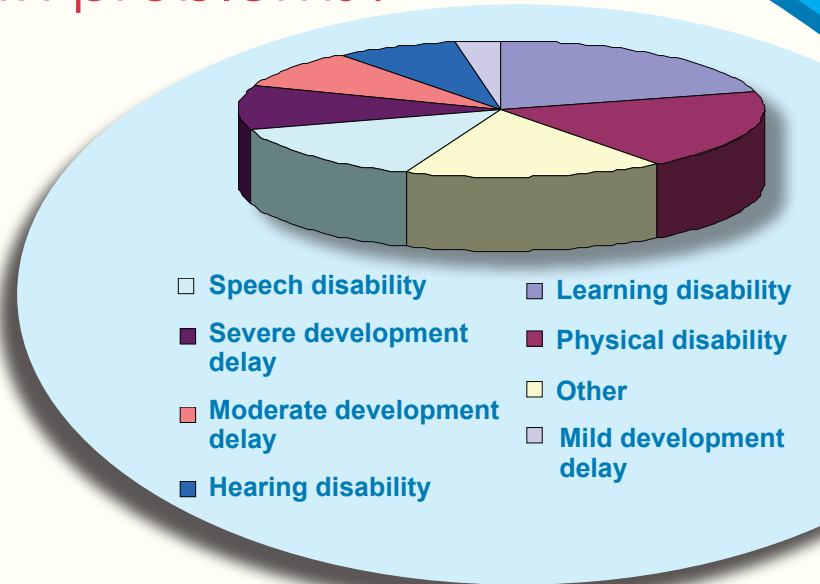
There are many primary diagnoses now on the Register, the most common eye and vision problems are shown here:



- | | |
|------------------------------|-------------------------------|
| ■ Cortical vision impairment | ■ Coloboma |
| ■ Oculocutaneous Albinism | ■ High Myopia |
| ■ Nystagmus | ■ Optic Atrophy |
| ■ Optic Nerve Hypoplasia | ■ Retinopathy of Prematurity |
| ■ Retinal Dystrophy | ■ Lebers Congenital Amaurosis |
| ■ Congenital Cataract | ■ Microphthalmos |
| | ■ Retinal detachment |
| | ■ Optic Nerve Glioma |

How many registered children have additional disabilities and other health problems?

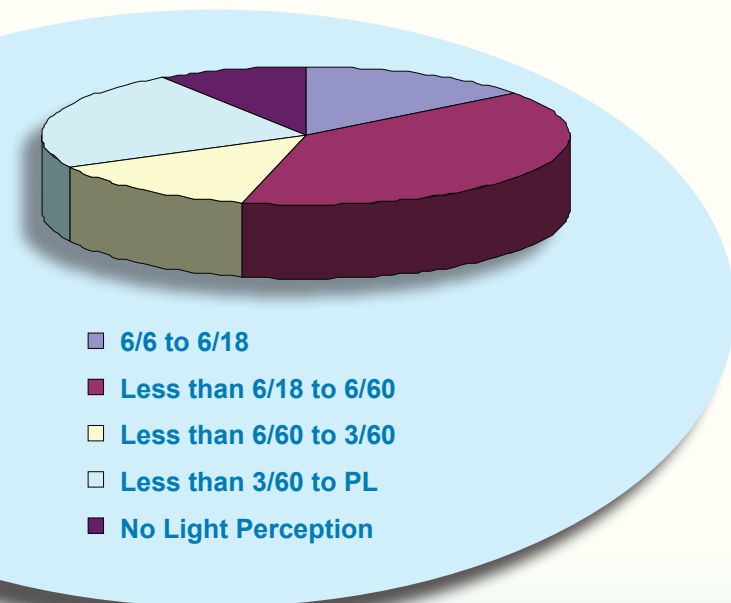
63% of families report their children having an additional disability other than vision impairment. These are shown on the right:



Levels of vision in registered children

Most eye health professionals have been able to provide an estimate of registered children's vision – known as visual acuity. 6/6 vision is usually the bottom or smallest line on a vision chart; 6/18 is about half way up a vision chart; and 6/60 is the top letter on a vision chart.

3/60 means that the top letter can be seen at a distance of 3 meters, and no longer at 6 meters. PL stands for perception of light which means light and dark only can be seen and the child isn't able to discriminate form or letters. Below indicates the level of vision of registered children:



Braille & Low Vision Aids

25% of registered children are Braille users and 80% of registered children use some type of low vision aid.

So you can see what an interesting snapshot of Australian childhood vision impairment we now have by examining the data families have kindly provided us. Now you have an idea about the findings you might find that your journey is similar to other families on the Register? Please feel free to think about posting in the Parent Forum and sharing your story with us.

How to contact us

You are welcome to make contact with the staff managing the Australian Childhood Vision Impairment Register at any time. We are always happy to hear from you, especially if you have something you would like to share with the other families on the Register. Please feel free to call or email us:

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Remember...

please register to join our Online Parent Forum – we're very pleased to offer this service to our parents and it will only be successful with everyone's involvement. Go to www.vifamilynetwork.org.au and follow the links to the forum.

